



## Original article

# A study of stigma among Iranian family caregivers of patients with multiple sclerosis: A descriptive explorative qualitative study



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## ABSTRACT

**Aim:** This study was done to investigate the experiences of family caregivers of people with multiple sclerosis (MS) about stigmatization in Iranian health care context.

**Background:** Stigmatization has been observed obviously among patients with MS but few studies have been conducted on stigma among the family caregivers of these patients.

**Methods:** This qualitative study with thematic analysis was done to explore this issue. Fourteen family caregivers of patients with MS were selected by purposive sampling. The data were collected through in-depth and unstructured interviews.

**Results:** Four main subthemes emerged from the analysis of the transcripts: “feeling shame”, “fear of being ridiculed by others”, “ignored by family” and “concealing disease to be secure against the perceptions of disease”.

**Conclusions:** Healthcare professionals should be encouraged to inform caregivers about social engagement strategies and to train them on the management of stigma as an important factor for the reduction of their social problems.

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## 1. Introduction

Multiple sclerosis (MS) is one of the most prevalent acute demyelinating inflammatory nervous system diseases which has involved many young adults. MS prevalence varies from 60 to 200 per 100,000 people in the United States (Lublin & Miller, 2008). Iran is considered a region of moderate prevalence of MS with 50,000 people affected (Saadatnia, Etemadifar, & Maghzi, 2007). The clinical progression of this disease may cause permanent debilitating, unclear and unpredictable complications which may lead to disorders in most dimensions of life, including emotional or behavioral functioning (Molina, Choi, Cella, & Rao, 2012). As MS progresses, the patients become functionally more and more dependent and unable to do their daily activities. Hence, they need to be cared for mostly by their families in the long term. Because the caring activities of family caregivers happen mainly in homes, most of these caregivers are ignored (Navab, Negarandeh, Peyrovi, & Navab, 2013; Masoudi, Sharifi Faradonbeh, Mobasheri, & Moghadasi, 2013). Due to the exhausting nature of MS and biological, social and psychological

demands of the MS patients, the caregivers may endure high levels of ambiguity and face many challenges) (Khayeri, Rabiei, Shamsalinia, & Masoudi, 2016; Masoudi, Abedi, Abedi, & Mohammadianinejad, 2015).

Two main features of Iranian culture which are also flourished by social expectations are amity and strong family relationships. Most Iranians tend to keep warm and sincere relationships with their family and to care for a sick family member stringently. Nowadays, it is obvious that the emphasis on MS patients care is moving from patient-centered approaches to a combined patient- and caregiver-centered ones because these factors are essential to the long-term caring for MS patients (Benito-León et al., 2011). Consequently, nursing a sick family member is a highly worthwhile and admirable act, chiefly among the Shias, such as Iranians. In this study, any prejudice about a person can influence both the patients and their family members (Navab et al., 2013).

MS can be considered both a medical event, with clinical and personal features, and a social event, with a scope beyond the patient's limitations (Grytten & Måseide, 2006). In Grytten and Maseide study, because of the unpredictability and progressively worsening conditions of nervous system in MS patients, these conditions are much more obvious throughout caring process in MS patients than in patients with other neurological disorders (Grytten & Måseide, 2005).

Most of studies have emphasized the psychological effects of MS on the caregivers. The results show that nursing a person with MS can have

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some adverse effects on the mental health of the caregiver (Bogosian, Moss-Morris, Yardley, & Dennison, 2009).

Many improvements have been achieved in medical care to increase survival rate. However, family caregivers are more likely to offer stricter care to the patients. The prevalence of emotional problems, such as stigmatization, is higher among the main family caregivers than other family members. Indeed, MS patients' family caregivers experience various degrees of psychosocial burden and stigmatization (Abendroth, Lutz, & Young, 2012).

Stigmatization is defined as a procedure in which people detect the unhealthy persons by assigning stereotypes to them inappropriately. The studies on stigma have mainly emphasized patient cooperation methods and the convenience of care. Besides that, scientific knowledge about stigma has focused mainly on supporting patient and family and preventing discrimination (Grytten & Måseide, 2006).

Goffman (1963) considered stigma a determining factor, which was defined mainly as experiences of being treated disrespectfully in specific social interchanges. He found that stigmatized people are ignored and forejudged. These conditions were likely to transfer from the stigmatized person to his or her close relatives (Goffman, 1963).

In a study by Werner et al. that explored the subjective experiences of family stigma reported by the children of patients with Alzheimer's disease, family stigma was one of the disfavored features of nursing a family member with neurological malfunction. They mentioned that family stigma was first experienced in three forms—lay public stigma, stigma of caregivers and structural stigma (Werner, Goldstein, & Buchbinder, 2010).

Stigma is a detrimental phenomenon for family because it limits the available social support and results in the seclusion of the stigmatized person (Navab et al., 2013). Family stigma was coined to refer to the stigma experienced by the close family caregivers of a stigmatized person. Family stigma damages the identity of family members because they are discriminated despite having normal characteristics (Navab et al., 2013). According to Grytten and Måseide (2006), depending on the intensity of the disease, patients with MS experience various dimensions of social distance and ignorance. They reported certain experiences such as being rejected or, in opposite, being paid too much attention in social dealings (Grytten & Måseide, 2006).

In Iran, MS can aggravate the vicious circle of the illness and negative social reactions, and lead to social exclusion and discrimination of both patients and family caregivers. Certain characteristics of MS (e.g. imbalance, tremors and debilitating symptoms) may be visible to others, resulting in stigmatization in social interactions and emotional, cognitive and physical disabilities (Grytten & Måseide, 2005).

When stigma and MS occur concurrently, MS may result in weaker self-care outcomes. Theorists have expressed some terms and features to define stigma's effects, including internalized stigma and enacted stigma. Momentous societal misunderstanding is a significant factor in the studies conducted on the populations of patients with neurological diseases. MS may cause different degrees of weakness and result in differences in the recurrence of stigmatizing incidents due to neurological malfunctions (Navab et al., 2013).

Molina et al. believes that when the negative viewpoints of the public affect people with degraded conditions, internalized stigma occurs (Corrigan & Penn, 1999; Corrigan & Watson, 2002). They may therefore experience various detrimental consequences (Corrigan, Watson, & Barr, 2006). Self-differentiation, manifested as self-demotion, has many detrimental effects resulting in the reduction in healthcare services use and poor quality of life and health outcomes (Fung, Tsang, & Chan, 2010; Rüşch et al., 2009). Major examples of these negative consequences are low self-confidence, low self-esteem and poor self-efficacy, which have been associated with loss of life management opportunities (Molina et al., 2012).

Regarding the disadvantages of being ignored and enacted stigma, the family caregivers of patients with less visible symptoms are not willing to reveal their patients' conditions even in medical settings (Molina et al., 2012).

In addition, studies have less frequently investigated stigma among the family caregivers of patients with MS, and no study has yet investigated this issue in Iran. Ghanean, Nojomi, and Jacobsson (2011) studied the stigmatization of people with emotional problems in Iran and reported 72% of these people were ignored, and thus isolated from society because of the negative attitudes toward mental disorders (Ghanean et al., 2011; Zarea, Nikbakht-Nasrabadi, Abbaszadeh, & Mohammadpour, 2012). Because most studies have focused on the patients and have not considered family caregivers, it is necessary to explore the experiences of the caregivers of MS patients about stigmatization. Therefore, the aim of this study is to investigate the experiences of family caregivers of people with MS about stigmatization in Iran health care context.

## 2. Methods

The study was conducted according to a qualitative and descriptive explorative method to explore the perspectives of the family caregivers of people with MS about stigmatization in Iran. For this purpose, a thematic analysis approach was adopted.

### 2.1. Participants and enrollment

The study was conducted from February 2012 to March 2013 in Shahrekord, Iran. The participants were 14 family caregivers that were selected purposively. When there is little information about a specific subject, unstructured interview can be helpful and the most well recognized fit for qualitative research studies (Kazemi, Nasrabadi, Hasanpour, Hassankhani, & Mills, 2011).

### 2.2. Data collection

Data gathering techniques in this study were observation and in-depth, unstructured interview. The interviews were conducted in Persian, and started with the core question: "Please explain about caring for a patient with MS." They asked the respondent to express their life experiences by their own explanation. In the case of indefiniteness, more detailed questions such as "What do you mean by ...?", "Please give an example?" and "Would you please think over on your explanation?" were asked. All the interviews were conducted in a calm and private environment, such as neurology department, Shahrekord, MS Society, or a neurologist office. The interviews were digitally recorded with an MP3 player and their duration varied from 45 to 100 min depending on the mental and physical conditions of the participants and their tolerance. In order to gather the data precisely, in addition to the recording of the interviews, field-note taking was conducted.

### 2.3. Data analysis

The data were analyzed based on the topics to determine the standards within the transcripts (Kazemi et al., 2011). After the first interview, data collection and elaboration were done simultaneously. The interviews were translated and written in Persian language verbatim by first author and then were analyzed. By means of the data collection and constant comparative analysis, the researcher will be able to ask more detailed questions in the next phase (Birks & Mills, 2011; Strauss & Corbin, 2008). At first, the researcher read and compared the transcripts with the recorded interviews to ensure the correct transcription of the respondents' replies. Then, they encoded the transcripts separately. Next, emerging codes were compared with previous codes using constant comparative analysis to examine the similarities or differences (Strauss & Corbin, 2008). Finally, after conducting 23 interviews, the codes lists were merged into themes until and the themes were saturated.

## 2.4. Rigor of research

In order to ensure the accuracy of the collected data, the multisource data collection technique was used. The transcripts of each interview and the field-notes were read several times by the researcher to achieve more precise knowledge about the collected data. In addition, the second and third authors listened to the recorded audio files and studied the written transcripts; each one of the transcripts was analyzed by all the authors (Charmaz, 2009; Heward, Molineux, & Gough, 2006; Lincoln & Guba, 1985). After the constant comparative analysis, member checking was done almost two months after the start of the interviews to provide the required interval for the in-depth analysis of the transcripts. All of the participants were called to clarify the interpretations of the transcripts; some cases of disagreement were discussed and the necessary corrections were made. During the sampling process, maximum variation was ensured. Besides that, reflective memos were used to enhance the audit trail (Mills, Bonner, & Francis, 2006). Prolonged engagement in the data collection for more than 14 months helped the researchers meet this purpose.

## 2.5. Ethical considerations

After obtaining the approval of the university's ethics committee, participants were informed about the research purposes and the data collection procedures in order to ensure them that the data are kept confidential. Participants were ensured that taking part in the study is voluntary, and that they can withdraw from the study at any time with no penalty. The location of the interviews was a quiet place with sufficient privacy and comfort. Before the interview, the participants provided a written informed consent to participate in the study.

## 3. Results

Out of the caregivers, seven were female and seven male, and their mean age was 34 (range: 20–45) years. The mean length of a caretaking day was nine hours. Regarding marital status, 9 (64.28%) were married and the rest were single. The majority ( $n = 11$  [78.57%]) of caregivers were housewives. Regarding education, the majority ( $n = 12$  [85.71%]) had high school completion certificate, and most were the spouse ( $n = 10$  [71.42%]) or daughter ( $n = 4$  [28.58%]) of the patient. First, more than 1374 first level codes emerged. After the classification and integration, eight categories were drawn. Finally, the theme “family caregiver's stigma” in this study was found to consist of four subthemes: “feeling shame due to others' awareness of the disease”, “fear of being ridiculed by others in society”, “being ignored by family” and “concealing disease to be secure against the perceptions of disease”.

The problematic dimensions of the disease became significant to the people who were influenced by social relationships. The participants expressed that the complex complications and disabilities due to the disease, such as imbalance, emotional bursts, depression, nervousness and urinary incontinence, made them react with feeling shame, fear of being ridiculed, being ignored and concealing disease.

### 3.1. Feeling shame due to others' awareness of the disease

The participants told that they did not feel comfortable in the society as they lacked the conventional rights to engage in social activities as a result of a sense of embarrassment and disdain due to the unnatural, unstable and sometimes unpleasant reactions and speech of their patients in the presence of other people, not only in social and larger scale interactions but also in limited gatherings such as among relatives. Thus, they trapped themselves in their homes which resulted in fewer social activities and feeling secluded from the society.

“Sometimes, when I go to the park with my mother, due to her urinary incontinence, (people) dishonor her which tortures me. They had negative reactions such as wonder and ridicule to us. They

muttered under their breaths that look at her girl, she doesn't clean her mother. I got embarrassed. Therefore, my mother was so upset and hasn't gone to the park for a long time.”

[Caregiver no. 14]

Another participant described the difficulties of being present in the society as follows:

“We go to a gathering and they (people) cut off their conversation when we approach. She's here, forget about it.... They want to stay distant from us, they don't like that we understand their utterances, sometimes they whisper something to each other and their eyes would turn toward us.”

[Caregiver no. 9]

“If we buy someone a present or a gift, they would quickly stop us and say you need your money to buy drugs for your patient, nobody expects you to do anything... I got very embarrassed and since then, we felt really bad and embarrassed because of their behavior. Our social relationships have thus decreased dramatically.”

[Caregiver no. 12]

### 3.2. Fear of being ridiculed by others in society

Being crippled and dependent on other members of the family or in some cases on social caregivers, caregivers and their patients have been exposed to mistreatment and misunderstanding. Participants were thus afraid of being ridiculed by others. One of the caregivers explained his patient's experience sitting on a wheelchair:

“When people saw him, they would say thank for God that we aren't handicapped like him. Sometimes, it happened that people laughed at him or made fun of him. I dislike when people backbite us in group. That's while my patient wasn't handicapped, he was disabled and had to use a wheelchair. When we go out, we feel bad and people don't accept us to go out like this, they keep looking at us and some of them even make fun of us.”

[Caregiver no. 3]

“... Sometimes when I lose my temper with my family members because of exhaustion and fatigue due to caring process, which is out of my hands, they would call me sicko sicko, it really hurts my feelings, it's embarrassing....”

[Caregiver no. 14]

“My brother is disabled. When I take his hand, (people) stand there and stare. This hurts me a lot... They probably think I am my brother's girlfriend [and] that's why he's holding my hand and helping me out....”

[Caregiver no. 7]

“At first when my mother didn't become crippled, we had gone to the bazaar for shopping and all of a sudden she lost her balance... she fell down, it was interesting that people were standing there and laughing at us and even wouldn't go away, I got embarrassed because of their behavior.”

[Caregiver no. 11]

“Sometimes, people make fun of him. Before being affected by this disease, he used to be an honorable man; unfortunately, I dislike getting him out or to parties. I don't like people talking about us in group. I have such a limited relationship.”

[Caregiver 11]

### 3.3. Being ignored by family

The functional appearance of MS and organic defect with observable signs and symptoms may be considered trivial factors based on medical



or biological references, but according to the experiences of these participants, they may be highly important from social perspectives. The visible and invisible symptoms of MS and lack of social interaction result in the rejection of the caregivers and patients in the society:

“Some people who don't know that these patients used to be honorable and respectful think negatively about them and their family. So, my social interactions have been mostly restricted due to some complex problems of my patients such as tremor, imbalance and urinary incontinence.”

[Caregiver no. 2]

“On the one hand, the problem of the costs has frustrated us; it's a great financial burden on the family and we're not being supported by others, and what's even more important is that emotional and financial supporters are not available. When you can't find these, it causes a tremendous level of stress for you. We were very upset because we are being ignored.”

[Caregiver no. 8]

“When the conditions of my mother were exacerbated, relatives abandoned us. When you go to buy groceries ..., (people) say to me why you are in shopping? Go to home and support your mother, why you came here! But, they did not come to meet her. I feel that they are afraid of her disease and avoid meeting her. Even they avoid me. I feel that both I and my mom were forgotten with the advent of the disease.”

[Caregiver no. 10]

### 3.4. Concealing disease to be secure against the perceptions of the disease

The family caregivers stated that they sometimes were stuck in a situation in which they had to hide their patients' disease. They mentioned that the complex conditions of the disease and insufficient information of people about MS arouse negative reactions such as astonishment and scoff. These disdainful behaviors damaged the personality of both the family caregivers and the patients. The caregivers were thus afraid of being exposed to others' negative perceptions of the disease.

“They (people) tell me your patient has collapsed and in a sense she is just a consumer contributing nothing useful just like a leech. This way you'll be smashed into pieces and crushed under the feet. Therefore, I keep her staying at home or prevent her from going out.”

[Caregiver no. 2]

All participants pointed to the curiosity others have toward their lives and in some cases the help and attention they receive because of others' inadequate knowledge, which may result in interference in their lives. These participants and their patients, depending on their dependence on others, were sometimes forced to surrender to decisions made by others in order to live with MS.

“... they're also curious to know what has happened and keep coming back and forth, a bunch of people that have nothing to do but to stick their noses into other people's business. You shouldn't disclose your patient disease too much for them to find out. They see you and they keep asking you did you find a good doctor? What did he say? Why did this happen to you and ....”

[Caregiver no. 14]

## 4. Discussion

This is the first investigation of the experiences of MS patients' family caregivers about stigmatization according to the statements of the caregivers in Iran, contributing to the relevant literature. Four sub-themes emerging from the main subject under study (family caregiver's

stigma) were widely and implicitly expressed by the family caregivers of people with MS.

A noticeable finding of the current study conducted in Iran context is the stigmatizing behaviors toward MS patients' family caregivers which were due to lack of information and insufficient knowledge about the disease. These findings are consistent with the results of Kazemi's study investigating the experiences of hemodialysis patients, and demonstrate that such social reactions may lead to the isolation of patients from social interactions, hinder their participation in the society and, in some way, deny them of their inalienable rights (Kazemi et al., 2011). Because of the chronic nature of MS, MS patients and their caregivers, as with hemodialysis patients, are worried about the negative and wrong judgments of others about this disease.

Moreover, Iran has an over 5000-year civilization (Mojtahed-Zadeh, 2007), and Islam is the main religion of this country (more than 95% of the population are Muslim) (World Health Organization, 2011). Social relationships are an important factor in nursing care for Muslim patients, chiefly according to the Shia teachings. Moreover, people, in the Iranian context, who receive help from their family caregivers are afraid of being negatively judged (such as being labeled as girlfriend or boyfriend, which is not accepted in Shia Islamic faith); therefore, in order to be safe against the social misperceptions of the disease, MS patients' caregivers have to deny themselves of their inalienable rights such as being comfortably present in the society and taking part in social activities and may be thus treated disrespectfully (Kazemi et al., 2011). Other studies in this field have also depicted chronic disease patients tending to hide their disease from others to keep themselves safe against adversity and disrespect (Hassankhani et al., 2010; Joachim & Acorn, 2000) [Joachim, 2000 #61; Hassankhani H, 2010 #62].

Although the literature shows that mentally ill people are less stigmatized and discriminated than physically ill ones, stigma is found in most patients with physical and mental disorders such as MS, as it has already been demonstrated in some studies (Navab et al., 2013; Masoudi et al., 2015). But, there are clear differences in the stereotypes, prejudice and resulting discrimination. Shibire et al. demonstrated the perception of stigma among family members of people with schizophrenia and major affective disorders in rural regions of Ethiopia, and argued that only a small proportion thought that it might be their fault that their family member had acquired the disease (with 4.5% endorsement), lower than the figures reported in the Western countries (Shibire et al., 2001).

In other contexts, research shows that the types of physical illness perceived to be severe or under personal control most probably result in social exclusion. Grytten & Måseide comprehensively discussed the rejection of people with conditions perceived to be their personal responsibility. This evidence is not in agreement with Goffman's assumption that conditions not being under personal control are more stigmatizing; as a result, the roles of the patients are not recognized, caused by the social disruption in interaction. They suggested that this apparent paradox refers to two different types of social exclusion (Grytten & Måseide, 2006).

Considering the experiences articulated by the respondents in this study, the unnatural and disdainful reactions toward MS disease may adversely influence the social personality and self-confidence of the caregivers. Being embarrassed due to others' awareness of the disease, disdainful and feeling shame are consequently provoked and the family caregiver are ignored (Joachim & Acorn, 2000) and stigmatized because of their interactions with MS patients (family stigma). The results of Larson and Corrigan (2008), consistent with the present study, confirmed that from emotional disorders perspective, family stigma is considered a special type of stigma that causes family caregivers to be stigmatized due to interaction with a person who has mental problems.

Goffman (1963) considered certain diseases such as mental disorders, cancer, epilepsy and AIDS to discuss the concept of stigma, and never linked stigma with MS (Goffman, 1963). In addition, in some studies on patients with facial deformity, cancer, arthritis and MS, it has been emphasized that the personal concepts of incapability and

weakness are considered a serious factor for any patients; therefore, stigmatizing behaviors toward these patients and their family caregivers were unique.

“Feeling shame due to the disease” was one of the main subthemes that represented the intrapersonal features in the family of MS patients. Several participants remarked that the caregivers of people with MS experienced feelings of being embarrassed and treated disrespectfully because of the negative and wrong judgments of others toward MS disease. Navab et al. (2013) referred to this feeling as “internal stigma” and described it as a sense of embarrassment that prevents the caregivers from seeking out others’ help (Navab et al., 2013).

“Fear of being ridiculed by others in society” was the second subtheme that represented the interpersonal aspect of family stigma. The participants discussed the unfair attitudes of the public and mentioned a constant fear of being ridiculed by others in society. They complained of the negative reactions of the public such as wonder, disrespect, ridicule and humiliation toward them. Navab et al., 2013 found another type of feeling shame and fear of being judged by others in the narratives written by the family members of patients with Alzheimer’s disease. They believed that unfair attitudes and behaviors of the public are “external stigma”, which is in fact equivalent to the discrimination concept of Goffman Theory (Navab et al., 2013). Goffman suggested that discrimination was due mainly to others’ biased reactions and behaviors rather than to the inequality in the distribution of public services (Goffman, 1971). Biased behavior negatively affects the personality of both the MS patients and their family caregivers because they are considered a single social unit due to their family relationships, especially in Iranian culture. Similarly, Goffman (1963) emphasized the communication of people with the stigmatized person and those who are socially dependent on them (Goffman, 1963).

The experience of being ignored and limited family relationships was the third subtheme, highlighting the social features of family stigma. All the respondents expressed the experiences of being much ignored, limited family relationships and being excluded by relatives, which emphasizes the harmful effects of nursing an MS patient on his/her caregiver. Therefore, the patients’ overall self-confidence and familial personality and identity may be damaged by stigmatization (Major & O’Brien, 2005). Consistently, Grytten and Maseide study on people with MS showed that the public either ignored MS patients or focused on them too much (Grytten & Maseide, 2006).

Concealing disease to be secure against the perceptions of the disease was the fourth subtheme emerging from the transcripts. This subtheme mainly represented the social aspect of family stigma. The participants in this study expressed their experiences with a great deal of internalized negative perceptions which indicated the negative impacts on the caregivers due to caring for MS patients. Grytten and Maseide believed that patients with MS and their families purposefully concealed disease or selectively disclosed it to be protected against social judgments or to enhance social belonging at work (Grytten & Maseide, 2005).

All of the participants in the study were afraid of being ridiculed; they had to isolate the patients or conceal their disease and themselves. Consequently, they avoid social interactions. Similarly, Werner et al. (2010) have confirmed these issues and declared that the caregivers’ reactions were considered a dimension of family stigma (Werner et al., 2010). Navab et al. (2013) highlighted hiding people with Alzheimer’s disease or the disease itself as a temporary strategy to manage family caregivers’ stigma. They concluded that although some family caregivers tried to manage the problematic conditions related to stigma, others who experienced family stigma avoided the situations in which the experience was likely to recur. Therefore, such reactions lead finally to the loneliness of the patient and the caregiver. They would hence avoid seeking out others’ help and endure many physical and mental problems (Navab et al., 2013).

Grytten and Maseide (2006) argued that the physical diseases which are chronic or under personal control will result in social isolation. They

classified the ignorance of the condition(s) diagnosed as the personal responsibility (Grytten & Maseide, 2006). These results are in an obvious disagreement with Goffman’s assumption (Goffman 71 and 63). Goffman believed that the situations that are not under personal control are more likely to be stigmatized; therefore, the role of the patient is not recognized due to social disconnection in interactions (Goffman, 1963). They believed that this obvious inconsistency is due to two different types of social isolation. The people who typically experience rejection appear to have the signs of control over the disease and those who cannot control themselves will receive too much attention. In social interactions, MS patients and their caregivers encounter severe problems in expressing MS conditions and managing the risk of inducing a sense of feeling ‘more ill’ in the presence of others.

Regarding that the stigmatization and discrimination of people with MS exist worldwide and need to be eliminated through public education and global and local campaigns, all such efforts should finally seek to prevent the isolation of MS patients and their family caregivers, and to facilitate social integration for them. Development of social and health policies for minimizing stigma must take into consideration some key issues such as access to care, financing health care and basic human rights. Driving privileges for MS patients’ family caregivers represents practical needs for policy to examine not only personal and public safety but also how it is that stigma, culture, liability and ethics do interact.

## 5. Conclusion

Family caregivers are invaluable agents of caring for patients with serious illnesses such as MS. Overall information about the experience of family stigma will help the family caregivers of MS patients find supportive and training methods to resolve this problem. It can be argued that having knowledge about MS may decrease the stigmatization and discrimination of MS patients and their caregivers. Therefore, it is necessary to improve the public awareness and information about MS. Moreover, empowering and educating family caregivers about the concept of stigma management may be an effective factor in decreasing their emotional disorders.

In Iran health care context, nurses are assumed to support and inform family caregivers by providing sufficient opportunity for them to discuss how it is that stigma does destroy their nursing roles. Compared to other countries, Iran health care professionals should make more efforts to educate people, at social scale, about MS, acceptance of such caregivers and funding support organizations for protecting family caregivers against stigma. In Iran context, it is important to support family caregivers through giving them advice about the emotional and social disorders experienced, and if necessary, to refer them to other health care professionals such as psychologists.

## 6. Limitations

As with any qualitative studies, the study findings of this study should be generalized to other settings *with caution* because the results of this study are limited to a specific environment of nursing home care in Ahvaz. However, the findings of this study can contribute to the information in this field.

## Conflict of interest

The authors have no conflict of interest to disclose.

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## References

- Abendroth, M., Lutz, B. J., & Young, M. E. (2012). Family caregivers' decision process to institutionalize persons with Parkinson's disease: A grounded theory study. *International Journal of Nursing Studies*, 49(4), 445–454. doi: S0020-7489(11)00400-7 [pii] 10.1016/j.ijnurstu.2011.10.003
- Benito-León, J., Rivera-Navarro, J., Guerrero, A. L., delas Heras, V., Balseiro, J., Rodríguez, E., ... Martínez-Martín, P. (2011). The CAREQOL-MS was a useful instrument to measure caregiver quality of life in multiple sclerosis. *Journal of Clinical Epidemiology*, 64(6), 675–686. <http://dx.doi.org/10.1016/j.jclinepi.2010.08.003>.
- Birks, M., & Mills, J. (2011). *Grounded theory: A practical guide*. London: Sage.
- Bogosian, A., Moss-Morris, R., Yardley, L., & Dennison, L. (2009). Experiences of partners of people in the early stages of multiple sclerosis. *Multiple Sclerosis*, 15(7), 876–884.
- Charmaz, K. (2009). In J. Morse, & P. N. Stern (Eds.), *Shifting the grounds: constructivist grounded theory methods*.
- Corrigan, P. W., & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, 54, 765–776.
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9(1), 35–53.
- Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*, 25(8), 875–884.
- Fung, K. M. T., Tsang, H. W. H., & Chan, F. (2010). Self-stigma, stages of change and psychosocial treatment adherence among Chinese people with schizophrenia: A path analysis. *Social Psychiatry and Psychiatric Epidemiology*, 45(5), 561–568.
- Ghaneian, H., Nojomi, M., & Jacobsson, L. (2011). Internalized stigma of mental illness in Tehran, Iran. *Stigma Research and Action*, 1(1), 11–17.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Goffman, E. (1971). *Relations in public. Microstudies of the public order*. London: Allen Lane/The Penguin Press.
- Grytten, N., & Måseide, P. (2005). What is expressed is not always what is felt: Coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. *Chronic Illness*, 1(3), 231–243.
- Grytten, N., & Måseide, P. (2006). 'When I am together with them I feel more ill.' The stigma of multiple sclerosis experienced in social relationships. *Chronic Illness*, 2(3), 195–208.
- Hassankhani, H., Taleghani, F., Mills, J., Birks, M., Francis, K., & Ahmadi, F. (2010). The challenges experienced by Iranian war veterans living with chemical warfare poisoning: A descriptive, exploratory study. *Scandinavian Journal of Caring Sciences*, 24(2), 290–298.
- Heward, K., Molineux, M., & Gough, B. (2006). A grounded theory analysis of the occupational impact of caring for a partner who has multiple sclerosis. *Journal of Occupational Science*, 13(2–3), 188–197.
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32(1), 243–248.
- Kazemi, M., Nasrabadi, A. N., Hasanpour, M., Hassankhani, H., & Mills, J. (2011). Experience of Iranian persons receiving hemodialysis: A descriptive, exploratory study. *Nursing & Health Sciences*, 13(1), 88–93. <http://dx.doi.org/10.1111/j.1442-2018.2011.00586.x>.
- Khayeri, F., Rabiei, L., Shamsalnia, A., & Masoudi, R. (2016). Effect of fordyce happiness model on depression, stress, anxiety, and fatigue in patients with multiplesclerosis. *Complementary Therapies in Clinical Practice*, 25, 130–135. <http://dx.doi.org/10.1016/j.ctcp.2016.09.009> Epub 2016 Sep 23.
- Larson, J., & Corrigan, P. (2008). The stigma of families with mental illness. *Academic Psychiatry*, 32(2), 87–91.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lublin, F. D., & Miller, A. E. (2008). Multiple sclerosis and other inflammatory demyelinating diseases of the central nervous system. In W. G. Bradley, R. B. Daroff, G. M. Fenichel, & J. Jankovic (Eds.), *Neurology in Clinical Practice (3 ed.)* Vol. 2. Philadelphia, PA: Butterworth-Heinemann.
- Major, B., & O'Brien, L. T. (2005). The social psychology of stigma. *Annual Review of Psychology*, 56, 393–421.
- Masoudi, R., Abedi, H., Abedi, P., & Mohammadianinejad, S. E. (2015). The perspectives of Iranian patients with multiple sclerosis on continuity of care: A qualitative study. *Journal of Nursing Research*, 23(2), 145–152. <http://dx.doi.org/10.1097/JNR.0000000000000070>.
- Masoudi, R., Sharifi Faradonbeh, A., Mobasheri, M., & Moghadasi, J. (2013). Evaluating the effectiveness of using a progressive muscle relaxation technique in reducing the pain of multiple sclerosis patients. *Journal of Musculoskeletal Pain*, 21(4), 350e357.
- Mills, J., Bonner, A., & Francis, K. (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*, 12(1), 8–13. doi: 10.1111/j.1440-172X.2006.00543.x [pii] 10.1111/j.1440-172X.2006.00543.x [doi].
- Mojtahed-Zadeh, P. (2007). Iran: An old civilization and a new nation state. *Focus on Geography*, 49(4), 20–32.
- Molina, Y., Choi, S. W., Cella, D., & Rao, D. (2012). The Stigma Scale for Chronic Illnesses 8-item version (SSCI-8): Development, validation and use across neurological conditions. *International Journal of Behavioral Medicine*, 1–11.
- Navab, E., Negarandeh, R., Peyrovi, H., & Navab, P. (2013). Stigma among Iranian family caregivers of patients with Alzheimer's disease: A hermeneutic study. *Nursing & Health Sciences*.
- Rüsch, N., Corrigan, P. W., Wassel, A., Michaels, P., Larson, J. E., Olschewski, M., ... Batia, K. (2009). Self-stigma, group identification, perceived legitimacy of discrimination and mental health service use. *The British Journal of Psychiatry*, 195(6), 551–552.
- Saadatnia, M., Etemadifar, M., & Maghzi, A. H. (2007). Multiple sclerosis in Isfahan, Iran. *International Review of Neurobiology*, 79, 357–375. [http://dx.doi.org/10.1016/s0074-7742\(07\)79016-5](http://dx.doi.org/10.1016/s0074-7742(07)79016-5).
- Shibre, T., Negash, A., Kullgren, G., Kebede, D., Alem, A., Fekadu, A., ... Jacobsson, L. (2001). Perception of stigma among family members of individuals with schizophrenia and major affective disorders in rural Ethiopia. *Social Psychiatry and Psychiatric Epidemiology*, 36(6), 299–303.
- Strauss, A. L., & Corbin, J. M. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. London: Sage.
- Werner, P., Goldstein, D., & Buchbinder, E. (2010). Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qualitative Health Research*, 20(2), 159–169.
- World Health Organization (2011). *World health statistics 2011*. World Health Organization.
- Zarea, K., Nikbakht-Nasrabadi, A., Abbaszadeh, A., & Mohammadpour, A. (2012). Facing the challenges and building solutions in clinical psychiatric nursing in Iran: A qualitative study. *Issues in Mental Health Nursing*, 33(10), 697–706.